

# Building a Progressive-Situational Model of Post-Diagnosis Information Seeking for Parents of Individuals with Down syndrome

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## ABSTRACT

This grounded theory study used in-depth, semi-structured interview to examine the information-seeking behaviors of 35 parents of children with Down syndrome. Emergent themes include a progressive pattern of behavior including information overload and avoidance, passive attention, and active information seeking; varying preferences between tacit and explicit information at different stages; and selection of information channels and sources that varied based on personal and situational constraints. Based on the findings, the author proposes a progressive model of health information seeking and a framework for using this model to collect data in practice. The author also discusses the practical and theoretical implications of a responsive, progressive approach to understanding parents' health information-seeking behavior.

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Health information-seeking behavior has been discussed in the nursing and information science literature increasingly since the early 1980s (Lambert & Loiselle, 2007). Over the past two decades, the evolving concept of patient-centered care (Robinson, Callister, Berry, & Dearing, 2008) has continued to shape understanding of health-related information seeking, and by extension, communication between health care providers and patients. As peer-to-peer information seeking and sharing, and more active co-management of care increase (Barry & Edgman-Levitan, 2012; Sadasivam et al., 2013), interest in studying patient information behavior has also increased (Street, Makoul, Arora, & Epstein, 2009). Studies on health literacy and patient information needs (e.g., Greenhalgh, 2015; Nutbeam, 2000; Zeng & Tse, 2006) have helped inform interactions between patients and medical professionals (Barry & Edgman-Levitan, 2012; Jones, Hampshire, Tweddle, Moulton, & Hill, 2001), and researchers have called for more nuanced investigations of patient behavior (Hupcey, Morse, Lenz, & Tasón, 1996; Morse, Hupcey, Mitcham, & Lenz, 1996; Schwartz-Barcott, 2003).

Although there are several ecological models of health behavior (Noar & Zimmerman, 2005; Sallis, Owen, & Fisher, 2008), little theory addresses health-related information seeking over time. Many health behavior and behavioral change models inform the *purpose* and *content* of health-related information through consideration of information as one of many factors in patient behavior, but information-seeking models focus more on the *process* of information provision in health care settings. For example, Johnson et al.'s (1995) comprehensive model of information seeking (CMIS) addresses individual and contextual factors of information seeking in terms of specific antecedents (based on Hochbaum's [1958] foundational health belief model), but approaches behavior as a single case, and action as the result of a relatively stable (and unchanging) causal structure, rather than as part of a progressive, responsive pattern of behavior. This article examines health-related information seeking as a progressive-situational process, explicitly acknowledging the effects of time, evolving motivations, and contextual constraints on information seeking. The article also proposes a scalable model of progressive information seeking in a health care setting, and discusses practical and theoretical implications of a progressive approach to understanding health-related information behavior and needs.

### **Objective and Phenomenon of Interest**

Because this article is based on findings of a larger grounded theory study, its focus is presented in terms of phenomenon of interest, rather than as a statement of research questions or hypotheses. The larger study builds a broad picture of parents' perceived *information worlds*, or the spheres within which they seek different types of information (Jaeger & Burnett, 2010). This examination centered parents as information seekers and managers and included an examination of actors and persistent roles, social norms that affected information behaviors, information values, and boundaries within information worlds (see Gibson, 2014, for more on this research). As part of the interview process, participants were asked to discuss incidents and experiences during which seeking and finding information were especially difficult. Participants were encouraged to discuss the period immediately following diagnosis in greater detail, as this represented a consistent theme. This article, specifically, presents substantive themes during the post-diagnosis period (description of progressive information behavior). The article also presents the Context/Behavior/Value/Channel (CBVC) Matrix, an abstracted form of the concept-indicator model (Charmaz, 2014; Strauss, 1987) that produced the substantive findings. This model

emerged during the analytical process, and provides a useful way for practitioners to capture patient behaviors, context, and information needs.

### *Why Down syndrome?*

Down syndrome is one of the most commonly diagnosed genetic conditions at birth in the United States (Presson et al., 2013). This meant that study participants across a range of racial, ethnic, and geographic groups could be recruited for this study. Continued research, and improvements in medicine, therapy, and education have improved quality of life for people with Down syndrome. This presents parents with a new, often complex body of information with which to engage after diagnosis. The transition into the information world (Jaeger & Burnett, 2010) of parents of children with Down syndrome is one that many parents make each year, and understanding that transition has implications for understanding other types of life-changing, but non-life threatening diagnoses.

### **Sensitizing Theory: Persons-in-Progressive-Situations and Life Course Theory**

The theoretical and methodological approaches presented in this article are influenced by two structurally similar progressive behavioral theories. Life course theory engages life stages as a series of progressive steps along “social pathways,” which comprise the “trajectories of life and work” (Elder, Johnson, & Crosnoe, 2003, p. 9). These pathways are negotiated (often retrospectively) in relation to individual motivation and socio-cultural contexts. Because life courses are cumulative representations of these steps, researchers using this approach sometimes ask participants to reflect on previous life stages (Elder, 1998) in light of current knowledge. In this study, the description of the “typical” life course is built from the sum of many parent reflections, given from the vantage point of different life stages. Having participants at a range of life stages offered a rich range of experiences and vantage points for evaluation, while still allowing for common patterns to emerge. The strongest themes (as presented in the findings) emerged despite differences in parent age, year of diagnosis, geography, or parent race. Parents of adult children were able to reflect on the usefulness of certain strategies, and were able to evaluate their actions and decisions without the immediacy of emotion that colored interviews with parents of younger children. This benefit is counterbalanced by the relative unreliability of participant accounts after the passage of time.

Similarly, Dunne’s (2002) model engages situationally and contextually dependent information seeking that is responsive to changing internal and external influences, as an individual progresses through time after a triggering or traumatic event to a safer, more resilient, state (Westbrook, 2008). As a situation progresses, the individual encounters new information gaps and experiences new triggers, and must renegotiate his or her information behaviors to achieve “mastery of life” (Savolainen, 1995, p. 264). Dunne’s research focuses on victims of intimate partner violence in particular, but her exploration of information behavior in response to this progression of intense emotional states has implications for information seeking post diagnosis. This approach shifts the focus of information seeking between patients and practitioners from individual occurrences approached on a case-by-case basis, to a more holistic, long-range view of patient information-seeking patterns, and provides a structured framework for examining and resolving information poverty and access issues in healthcare settings.

## **Disability and Parent Information Seeking**

Studies of disability diagnoses have found that parents exhibit a fairly consistent range of post-diagnosis information behaviors, including avoidance and denial (Bingham, Correa, & Huber, 2012), passive receipt of information, active information seeking (Jessup, Shields, Branch-Smith, Douglas, 2013; Neill et al., 2015), and hoarding. Studies have also found that parents exhibit a range of emotional reactions and associated coping mechanisms, with experiences heavily influenced by the diagnostic experience (Graungaard & Skov, 2007; Skotko, 2005). Parents sometimes cope with early shock and emotional distress through information avoidance or inaction (Case, Andrews, Johnson, Allard, 2005; Van Riper, 2007; Wilson, 2000), or might seek to exert control or mitigate uncertainty through information seeking or information hoarding (Rodrigue, Morgan, Geffken, 1992). Although these studies have found fairly consistent emotional and information behavior, they largely focus on parents' behaviors at a particular point in time, rather than over time. This makes problems, such as persistent lack of information, difficult to identify.

## **Method**

### *Symbolic Interactionism and Grounded Theory*

This qualitative study takes a family-centered methodological and theoretical approach to examining parents' health information seeking. A constructivist grounded theory approach (Charmaz, 2014; Corbin & Strauss, 2008) assumes that any interpretation of data is a single representation of multiple realities, co-constructed among participants and researchers. As such, objectivity is not a goal. Instead, the researcher works to faithfully represent participant responses and interpret those responses through her or his own layer of personal, theoretical, and professional lenses. Through this symbolic interactionist lens, self-reported data, such as the in-person interview and the mapping done in this study, result from a negotiation among numerous factors, including the researcher's choice of questions and personal presentation (including identity), participant identity, memory, and intention (Jeon, 2004). As the mother of a child with Down syndrome, the researcher had knowledge that helped build rapport with participants, and gave insights into question selection, phrasing, and data analysis (Charmaz, 2014; Heath & Cowley, 2004).

This focus on participant perspectives is important when studying information access and behavior because participant awareness of and ability to access information sources, rather than the mere existence of information sources, determine functional information access. Understanding how patients and caretakers perceive the diagnostic experience and the information available to them during this experience is necessary for the creation of information systems (human and machine) that meet their needs.

### *Sensitizing Theory: Information Worlds*

The theory of information worlds (Burnett, 2015; Jaeger & Burnett, 2010) acknowledges this concept of co-constructed realities and mutuality through the boundary concept, which focuses on shared meanings and conflicts as they occur at the edges of information worlds (Jaeger & Burnett, 2010). The diagnostic experience, where parent and practitioner information worlds meet (sometimes with conflicting language, priorities, and perspectives), is an example of such a boundary. Information worlds theory is useful for guiding grounded theory data collection as it provides a framework for describing actors, information

behaviors, information values, and boundaries within and between information worlds without imposing specific coding categories (Charmaz, 2014; Corbin & Strauss, 2008).

### *Sample and Recruiting*

Thirty-five parents of individuals with Down syndrome from two urban counties in Southeastern United States engaged in confidential semi-structured in-depth interviews about their information-seeking/sharing behavior and their information needs. A theoretical sampling approach was taken to participant recruiting; purposive and snowball sampling methods were used to create the study sample. Theoretical sampling (a nonprobability sampling approach commonly used in grounded theory research) guides development of a study sample by focusing primarily on rich development of emergent themes (Charmaz, 2014; Corbin Strauss, 1990). Once an initial batch of data was collected, additional participants provided data for constant comparison, or testing of conceptual models as they developed. Participants were initially recruited via the email list and Facebook group membership of local parent-support groups, and were asked to forward the solicitation to peers who were not on the support group list. The solicitation email disclosed the researcher's status as the parent of a child with Down syndrome. Theoretical saturation was assumed when explicit responses to pre-planned interview questions were repeated by at least three respondents in each case.

Initial interviews occurred between June 2011 and December 2012. Of the initial sample of 28 participants, 27 were women between the ages of 25 and 70 years. One was male. Three self-identified as Black or African American, and 25 identified as White. Three identified as Hispanic or Latino. No systematic data were collected about participants' other children, as this was not the focus of this study. After initial data analysis, a more racially and geographically heterogeneous sample was recruited (between July of 2014 and June of 2015) to respond to theoretical concerns about the homogeneity of the initial sample. The final expanded sample included 35 parents from five states (Texas, California, North Carolina, Florida, and Georgia). Of this final group of respondents, six were Black or African American, 29 were White, and five identified as Hispanic or Latino and White. Participants ranged in age from 26 to 73 years (*M* reported age = 44 years), and their children's ages ranged from 3 months to 38 years (*M* reported age = 11 years; see Table 1 for age distribution of children). Of the participants, 30 were married and five were unmarried (four divorced, one widowed).

Although they were not asked explicitly about their previous knowledge about Down syndrome, participants described varying amounts and types of previous knowledge about Down syndrome that ranged from interactions with people with Down syndrome in their own childhoods and previous lives to professional medical knowledge about Down syndrome. Four participants worked professionally with children with special needs (including Down syndrome) as part of their careers (as teachers and therapists).

**Table 1.** Participants by Child Age.

Child		
Age	Life Stage	No. of Participants
0–3	Early childhood/early intervention	9
4–10	Elementary school	12
11–17	Middle/high school	6
18–22	Post-secondary/college	4
22+	Adulthood	4

### *Interviews*

Informed consent was obtained from study participants prior to interviews. Confidential interviews ranged between 17 and 90 minutes (*M* interview length = 63 minutes). Interviews were audio recorded and transcribed by the researcher, with names and other explicit personally identifiable data removed before analysis.

The interview instrument was adapted from the information horizons mapping survey (Sonnenwald, Wildemuth, & Harmon, 2001), which is designed to elicit a wide range of information about participants' information-seeking experiences and strategies. Participants were asked questions about their information needs and seeking over the previous year, and then to describe situations in which they felt that they could not find enough information (at any point during their child's lifetime), in which they had experienced information overload, and in which they had just the right amount of information to make a decision. The expansion of the chronological scope from the experiences of the previous year to the entire life span had a dual purpose. This incorporation of retrospective reflection (Stefl-Mabry, Dequoy, & Stevens, 2012) into the interview was a systematic response to early insistence by participants that their most prominent memories of information overload had occurred after diagnosis (for most participants, this was after birth). This strategy was supported, conceptually, by the reflective life course approach that framed the study. Retrospective reflection allows the individual to contemplate an experience with the benefit of hindsight. For example, one mother described the feeling of information overload immediately post diagnosis as instrumental to her developing a selective strategy for seeking later on. She realized that she would need to intentionally limit the amount of information she sought. Participants were asked to give advice to a hypothetical parent of a newborn with Down syndrome and to describe and assess the strength of their community of support. This mother advised new parents to limit their information seeking to parents 1 year beyond her child's age.

### *Data Analysis*

Data were collected and analyzed iteratively, in several rounds of one to two interviews per round. Coding of interview data involved three types of coding (Charmaz, 2014): open coding (initial identification of phenomena, concepts, and themes/categories), axial coding (identifying properties, dimensions, and context surrounding previously identified of concepts, themes, and categories), and selective coding (identifying relationships between

themes; Corbin & Strauss, 2008; Strauss & Corbin, 1998). Axial coding focused on identifying five components of identified phenomena (Identification/naming, Process, Context, Motivation, and Effect) through examination of sensitizing questions (Charmaz, 2014; Strauss & Corbin, 1998). Table 2 provides a sample of axial coding for the Process category (in vivo codes are italicized). This round of axial coding examined how and when a phenomenon occurred, and how it developed over time. Similar analysis was done for each of the five categories.

Trustworthiness was ensured through constant comparison, coding and recoding (over time), and member checking (Corbin & Strauss, 1990) with participants during and after data analysis. Constant comparison was used to ensure the appropriateness of codes and categories, and to continually incorporate new concepts as articulated by the participants. Extensive memoing was used throughout the data collection and analysis to note observations and as a check on researcher bias. A scan for already existing models to describe behavioral patterns emerging from the data was done after coding (Charmaz, 2014).

## Findings

Data analysis resulted in two models. The first is a substantive behavioral model that comprises themes present in this particular data set (and for this particular sample of individuals and contexts). The second, the CBVC model, is a concept-indicator model that emerges from the data as an abstracted version of the coding structure used for data analysis, but provides a practical tool for practitioners seeking to apply a similar process to recording and analyzing patient or caretaker information behavior in contexts beyond the one examined in this study.

Emergent themes are organized in terms of *information behaviors*, or actions taken in response to information needs; *information channel* preferences, or pathways between information seeker and information source/medium; and *information values*, or preferences manifested as statements about the importance of certain types information and information behaviors (Jaeger & Burnett, 2010). For the most part, parents began with avoidance (or at least avoidance of unnecessary information), followed by passive acceptance, and followed by active information seeking. The theme of *tacit knowledge*, or experiential knowledge that is difficult to impart using spoken or written words (Kothari et al., 2012; Wyatt, 2001), was interwoven throughout participant descriptions of their broader information-seeking patterns. For participants, this tacit knowledge included information about quality of life with Down syndrome, family stability, and sense of self-worth. This knowledge was often paired with emotional support, but also involved development of understanding about what it would mean to be the parent (or a family) of a child with Down syndrome. These themes are described in more depth below.

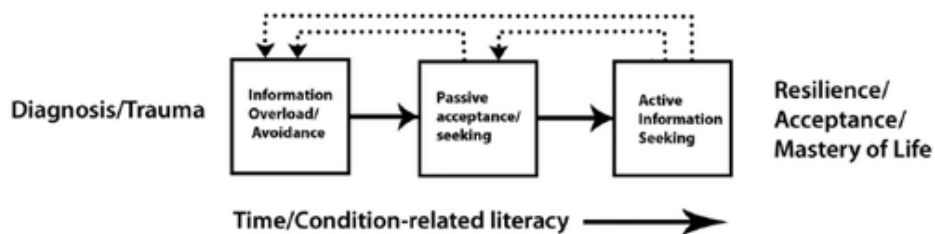
**Table 2.** Process Categories and Open Codes.

Information Behavior	Process Category	Open Codes (Previously Identified)
Information affordance	emotion/thoughts (personal constraint)	<i>in shock</i> ; curiosity; fear; sadness; anger; guilt; <i>worthless</i> ; <i>nothing I didn't expect</i> ; <i>total surprise</i> ; <i>intense</i> ; <i>overwhelming</i> ; <i>freaking out</i>
	self-evaluation (personal constraint)	uninformed / <i>didn't understand</i> ; guilt; avoidance; <i>didn't want to deal</i> ; needed hope; <i>adjustment period</i>
	Behavior (result)	avoiding; <i>being sad</i> ; protecting
	Time (situational constraint)	<i>Initially</i> ; <i>at first</i> ; <i>when we moved</i> ; immediately after birth; new/ emotionally challenging space
Passive attention/ seeking	emotion/thoughts (personal constraint)	<i>a blur</i> ; speed/ <i>happened so fast</i>
	self-evaluation (personal constraint)	<i>if I had known</i> ; <i>stabilized</i> ; dependent
	behavior (result)	<i>do what you gotta do</i> ; <i>they said</i> ; listening; <i>went to the appointment</i> ; receiving information; agreeing/consenting (to services/treatment); asking others to search
	Time (situational constraint)	<i>Then a little later</i> ; <i>when we got over the shock</i> ; <i>when she was a little older</i> ; intermediate stage; coming to acceptance; busy times; other things taking priority
Active information seeking	emotion/thoughts (personal constraint)	<i>always feel like I don't have enough information</i> ; <i>didn't realize how little I knew</i> ; guilt; surprise; anger; frustration; eagerness; joy; courage; determination
	self-evaluation (personal constraint)	proactive; selective; <i>controlling</i> ; <i>know better</i>
	behavior (result)	<i>be proactive</i> ; <i>be selective</i> ; mentoring; apprenticing; asking; demanding; searching; hoarding; exchanging; encountering; choosing
	Time (situational constraint)	<i>Immediately</i> ; <i>a few years later</i> ; initial; secondary; tertiary

Figure 1 illustrates the range of self-described parent information behaviors after diagnosis, categorized into three general themes: avoidance, passive information seeking, and active information seeking. Although participants described a fairly consistent progression of



information behaviors, they described differences in timing that suggested an inverse relationship between emotionally negative experiences and speed of parent progression to active seeking. Parents who had particularly negative emotional experiences in the period immediately after diagnosis tended to avoid active information seeking and making connections with other families of individuals with Down syndrome for much longer periods of time (some for several years). Although the timing and strength of these behaviors were complex and varied (and some parents repeated stages of behavior, as represented by dotted lines), parents exhibited a fairly consistent progression of responses over time. Parents who had worked with people with Down syndrome prior to the births of their own children demonstrated a similar progression of behavior, but focused their information seeking primarily on tacit information about parenting and their own emotional well-being.



**Figure 1.** Model of post-diagnosis information-seeking behavior.

#### *Information Behaviors*

**Avoidance.** Avoidance of explicit information (spoken or written facts) in the period immediately after diagnosis was a strong theme among participants. Many parents framed diagnosis as an emotionally traumatic event, and initial information avoidance as a means of coping with a sense of being overwhelmed by emotion, shock at a sudden change in circumstances, and a loss of the expected (as described by Morse, 2011). Some avoided information altogether, whereas others immediately sought out only what they perceived as salient basic explicit information about Down syndrome, avoiding information they perceived as unnecessary. One mother said,

I did not need to know that one in five kids, or one in 500? I don't know what the stat is . . . turn into leukemia . . . I mean, just because that happens with one in 500 kids (and I don't know the actual number), doesn't mean it's going to mine, and that's way too much knowledge, or information. It's irrelevant.

For some, this initial rejection of statistical information indicated a temporary difference between the priorities of the clinician and those of the parent. Parents described initial information needs as more focused on facilitating immediate action and gaining tacit knowledge about living life with Down syndrome and general well-being. Most salient information answered the question, "What does this diagnosis mean for my child, and my family?" Although participants expressed resentment toward individuals and information that "took away hope," they were fully aware that providers had a responsibility to provide balanced, thorough information, and were willing to accept and store "less pertinent" written information until they felt ready to use it. Some participants explicitly acknowledged the value of this early information, when provided in written form that they could consult at a later time. When asked whether she would rather not have received what she had described as "tons of

statics” about Down syndrome–related illnesses, one mother replied, “I think it’s better to have all that stuff and be able to push it aside than to not have all that stuff.”

This description of shock and emotional numbness was consistent with previous studies on diagnosis (Hamburg & Adams, 1967; Van Riper, 2007). Within the first few weeks after birth, many participants simultaneously engaged in medical decision making and information avoidance. This combination of behaviors raises some concern about these parents’ ability to properly comprehend medical information and willingness to ask questions about risks and treatment (Weston, 2001).

Participants consistently prioritized their need for tacit information about the future well-being of their newborns, themselves, and their families in the period immediately following diagnosis. Some participants described fear as a motivator for information avoidance. One mother reflected on her desire for more tacit knowledge about her daughter at birth and her knowledge a few years later:

I was in an adjustment period . . . and so I would sometimes actually block information at the very beginning because I wasn’t emotionally stable at that point, to receive it. And I didn’t understand—I mean it was ignorance . . . if I had a video of my daughter at 3 years old that somebody showed me when she was first born, I’d go “oh!” you know, she’s delightful . . . but, when she’s first born, you know, all I had was a, was a piece of paper.

For some participants, a knowledgeable, confident, and encouraging pediatrician was able to provide this reassurance. In some cases, clinicians framed the birth of the child in a negative light, expressing condolences, and offering dim prognoses for quality of life. The resulting negative emotions led some participants to avoid contacting other parents or parent-support groups, for fear of being For some participants, a knowledgeable, confident, and encouraging pediatrician was able to provide this reassurance. In some cases, clinicians framed the birth of the child in a negative light, expressing condolences, and offering dim prognoses for quality of life. The resulting negative emotions led some participants to avoid contacting other parents or parent-support groups, for fear of being associated with a community of individuals who might reinforce a negative or dim outlook they had received from their doctors. One mother commented,

So it was a total surprise for us—we didn’t expect it. And the picture that they paint is very negative, so you go through that stage, of three months of not accepting it, but just being sad, but we shouldn’t, because what comes along is amazing. And, I just didn’t want to deal with anybody that had to do with Down syndrome, and were going to tell me the worst things, or see things that I didn’t want to see.

*Passive acceptance.* For the majority of the participants, the transition between information avoidance and active information seeking was intermediated by a period of passive attention (Wilson, 1997, 2000) to information. One participant described this period as “being on autopilot,” in that she listened to her care team and read medical literature given to her, but did not actively ask questions or volunteer information. During this phase, participants were willing to receive information, but did not actively engage in information seeking about medical options, or explore alternatives. Some participants temporarily delegated

responsibility for seeking information to their spouses, family members, or friends. One participant said, “my husband had to go home and Google it, because we didn’t even know, we were like ‘what’s really Down Syndrome?’” Physical exhaustion, emotional vulnerability, and lack of information literacy were all cited as reasons for passive attention to information. As time passed, participants transitioned from passive acceptance into the active information seeking and sharing that defined participation in the local parent information network and more proactive doctor–patient relationships.

*Active information seeking.* Participants described active information seeking as fairly intensive and process-oriented. “Looking for information” was a learned skill, and for some, an almost constant state of action (or state of being). Participants who transitioned into active seeking soon after birth (while still in the hospital) valued practical information about the first year of raising a baby with Down syndrome. Participants described pediatricians, nurses, therapists, geneticists, and mentor parents as trusted sources for this information. For most, these information needs branched off into several other health- and development-related information needs.

As children aged, parents had fewer new information needs and strengthened their local information networks, enabling them to focus on maintaining routine, rather than seeking new sources of information. *They developed patterns and habits for seeking information about their children’s particular needs, and developed more specialized knowledge about local information environments.* One parent commented, “I think brand new parents get overdosed with almost too much. It’s information overload. Then once you’re stabilized, then it’s like any other kid.”

Before and during periods of transition (e.g., moving to a new school system, or to a new doctor or specialist), many participants began the information-seeking cycle all over again, albeit in a more gradual, less emotionally intense way. Prior to transitions, many discussed avoidance (not thinking about the upcoming transition, or procrastinating instead of looking for information), moving into passive information seeking (or environmental scanning), and then into active information seeking. For many participants, once they moved into active information seeking, there was “no such thing as information overload.” At this point, parents valued depth of knowledge about their children’s specific medical conditions and developmental issues, and considered withholding of that information to be a problematic behavior on the part of professionals. This is a contrast to participants’ discussion of the newborn period, when they preferred that information be filtered and prioritized.

#### *Information Values: Tacit Knowledge Versus Explicit Information*

The theme of tacit knowledge, or experiential knowledge that is difficult to impart using spoken or written words (Kothari et al., 2012; Wyatt, 2001), was interwoven throughout participant descriptions of their broader information-seeking patterns. For participants, this tacit knowledge included information about quality of life with Down syndrome, family stability, and sense of self-worth. This knowledge was often paired with emotional support but also involved development of understanding about what it would mean to be the parent (or a family) of a child with Down syndrome. One mother wrote that she wished she could “just be a fly on the wall of the family of a 15 year old, or a 22 year old, or a 4 year old, to see what their life is like.”

Participants indicated that more experienced parents of other children with Down syndrome were a primary source of tacit information. Many new mothers of babies with disabilities confront issues related to self-worth, self-blame, and guilt (Kucik, Shin, Siffel, Marengo, & Correa, 2013; Skotko, 2005). In several cases, mothers said that meeting more experienced, “intelligent, well-spoken, and happy” mothers helped them by assuring them that future happiness was possible, but they also validated the information and suggestions given by medical professionals and social workers. In the short term, more experienced parents served as a source of hope. Because these mothers had followed similar medical advice and were well adjusted with happy families, they served as living endorsements of clinician expertise. In the longer term, these more experienced parents acted as cognitive authorities, or mentors, whose lives and experiences provided new mothers with confidence and hope for future well-being, but also served as roadmaps that newer families could follow or avoid. One mother described a hospital visit from two mothers from the local support group:

The night my daughter was born, there were two mothers right there to assure me that there were services, and to assure me that I was not some degenerate, or drug abuser. And they were attractive and intelligent women that gave me the feeling that, oh, okay, so other people do this. So that was very very helpful with me.

In addition to providing emotional reassurance and tacit knowledge about future well-being, more experienced parents provided an alternative to the medical focus of clinicians. One mother, who mentored new mothers, gave the following advice:

This baby is only going to be baby for a little while, just like any other baby, and so what we tell you to do, is enjoy your baby. There's time for all this other stuff. And you want to be cognizant of the fact that the baby has a developmental disability, but in terms of “what does this baby need?” This baby needs lots of love, food, sleep and poop. That's it. Just like every other baby.

For many participants, the experience associated with transfer of this tacit knowledge also served to initiate the new parent into a stratified, mostly local system of network-mediated legitimation (Haythornthwaite, 1996; Veinot, 2009). Network-mediated legitimation refers to the mechanism by which individuals within the community serve as cognitive authorities for the purpose of finding and verifying information, and making referrals.

#### *Context/Behavior/Value/Channel Model*

This model (Table 3) describes an evolving approach to information seeking, moving from avoidance of explicit information and passive acceptance of tacit knowledge about Down syndrome to active seeking of explicit information about Down syndrome and tacit knowledge about raising a child with Down syndrome. The matrix also describes internal and external factors that might have influenced behaviors, and preferred information-seeking channels (Spink & Cole, 2001) for information seeking at each stage. It gives the researcher (or a practitioner) a comprehensive history of information-seeking behaviors and associated factors, a sense of the trajectory of this individual's information-seeking process, and cues as to what factors might be relevant in choosing strategies for communication with the individual.

#### *Information Channels*

Parent information source preferences followed four channels: *person to self* (P-S), which included memories, perceptions, and conscious decisions; *person to person* (P-P), which included communications, information seeking, and exchange between the participant and another individual; *person to network* (P-N), which involved the participant and a network or loosely affiliated group of individuals (such as a support group or online forum); and *person to organization* (P-O), which involved the participant and a formal organization or agency.

**Table 3.** Example of CBVC Matrix for Participant 22T.

Time/Events	Day 1/Birth	Day 7/Baby Released From Hospital	Third Month
Personal constraints	Emotions: shock, fear, grief	Emotions: hopeful, determined, sadness, exhausted, fear, relief	Emotions: hopeful; more emotionally secure; happier; still tired; determined
	Little previous knowledge about Down syndrome	Little knowledge about interacting with/ raising child with Down syndrome	Curious about other families.
	Negative personal perception of Down syndrome	Did not want to meet other families	Guarded about lowered expectations of others.
Situational constraints	Post-natal diagnosis	Follow-ups with local pediatrician.	Urban home setting
	In hospital—regional medical center	Loss of daily access to specialists (cardiologist, NICU personnel, and so forth)	Others: ? (none discussed)
	No access to vetted information	Needed to arrange local services (assessment and therapy)	
	Negative approach to diagnosis from doctor/care team	Urban home setting; “supportive” caseworker	
Information behaviors	Avoidance (of explicit info.)	Avoidance (of tacit knowledge)	Active seeking (explicit info)
	Passive acceptance (of tacit knowledge)	Passive acceptance (of explicit information about therapy and services; basic info about Down syndrome)	Active seeking (tacit info)
		Active seeking (of information about therapy/services)	

Info. values	Tacit knowledge preferred	Selective preferences for Tacit/Explicit	Tacit and explicit
Info channels	Face-to-face (P-P) (doctors, nurses, other family members, spouse)	Face-to-face (P-P; P-S; P-O); Internet (P-P; P-O)	

Note. CBVC = Context/Behavior/Value/Channel; P-P = person to person; P-S = person to self; P-O = person to organization; NICU = Neonatal Intensive Care Unit.

## Discussion

Participants described a fairly consistent (but not completely uniform) progression of information behaviors (moving from initial information avoidance to progressively active information seeking) that is consistent with previous research on the emotional states of parents after Down syndrome diagnoses (Nelson Goff et al., 2013; Poehlmann, Clements, Abbeduto, & Farsad, 2005). Although the speed of progression varied with individual context, and some parents repeated portions of this pattern (moving between periods of avoidance and active information seeking at points of transition, such as release from the hospital), the general progression from avoidance to active seeking was found among parents in all age and race groups, and among parents with children in all age groups.

### *Fostering Connections*

Research has shown that prolonged cognitive avoidance after diagnosis is associated with poor long-term adjustment and lowered resilience (Stanton, Danoff-Burg, & Huggins, 2002). For parents of children with Down syndrome, this means that helping parents adjust to purposive information seeking could potentially improve long-term well-being for newborns and their families. Maladjustment might mean parents not seeking early information and intervention services such as therapies, or not following up with pediatricians regarding medical diagnoses and treatments. For participants, two types of connections helped foster positive emotional reactions and increased their willingness and/or ability to actively seek and exchange information: strong connections with positive medical professionals (doctors or nurses) and personal connections with other parents of individuals with Down syndrome.

Contact with other local families (in person or via the Internet) and online resources that describe day-to-day family life with individuals with Down syndrome (such as personal blogs, YouTube Channels, or Facebook groups) were both cited by study participants as helpful tools for connecting them to local networks of parents as well as wider communities. Partnerships with local parent organizations (when available) provide the opportunity for parents to engage with parent mentors. Technology and media offer possible means for reducing barriers for entry into local parent groups, and for meeting needs in areas without parent-support groups (Liu et al., 2011). Formalized partnerships between hospitals and parent groups could facilitate this type of knowledge transfer and help educate parents about common concerns during the baby's first year of life in a way that is also emotionally supportive and meets tacit and explicit information needs.

### *From Bad News to Mastery of Life*

Although a Down syndrome diagnosis can be emotionally difficult for a parent, it differs from other types of diagnoses in that it does not progress to a tragic event. Whereas cancer or

injury diagnoses are focused on helping patients and caretakers cope with loss of life or life function as they progress (temporally and emotionally) toward a tragic event, a Down syndrome diagnosis involves a “period of grieving for the loss of . . . the expected” (Morse, 2011, p. 197) and movement toward acceptance, or what Savolainen (1995) calls “mastery of life” (p. 259). Dunne’s (2002) model, which focuses on an individual’s progress from a traumatic experience to peace, provides a useful approach to helping people use information to make emotional and practical transitions. This approach differentiates information seeking and use for someone receiving a developmental disability diagnosis (like Down syndrome), and diagnosis of terminal disease (like cancer) or injury. In this study, participants overwhelmingly described early emotional responses as transitional, but for the most part, progressively positive. It is possible that this difference—between progression to trauma, and progression away from trauma—informs the timing and urgency of information provision, and suggests that contact with other parents who have come closer to achieving mastery of life would be beneficial for new parents. Future research is needed to further examine these differences.

### *Recommendations for Practice*

Maintaining awareness of (and recording) information-seeking behavior as a progressive continuum, rather than as a series of individual events, could help practitioners build more holistic models of care, and help improve continuity of care (especially in team-based settings). The CBVC model gives practitioners a framework for understanding and recording patient information-seeking behavior. Explicit acknowledgment and recording of personal constraints (e.g., emotions, life events, and affective states), situational constraints (e.g., life events), associated information behaviors, and preferred information channels give medical professionals a cache of data that is useful for personalizing services to patients and to better meet information needs. This cache of data can be the result of observation, or self-report. Although this study focused on behaviors after receiving a Down syndrome diagnosis, this approach is not limited to Down syndrome diagnoses; it is potentially useful for recording other patient information behavior related to any incidents or diagnosis with a discernible starting point.

### *Limitations*

This exploratory grounded theory study relies on a body of self-reported interview data, which is limited in its verifiability. The wide age range of children whose parents were included in this study enabled development of a progressive model through retrospective reflection (Steffl-Mabry et al., 2012) over emotionally fraught information-seeking experiences. This represents a benefit and a limitation. Retrospective reflection allows the individual to contemplate and evaluate an experience with the benefit of accumulated knowledge, but presents a limitation, as self-reported data become less reliable over time. The risk of reduced reliability was somewhat balanced by the increase in the number of participants, and the expansion of the sample to include a more geographically and racially diverse sample. The consistency of participant accounts across the sample suggested that accounts were trustworthy.

Although participants were consistent in their general progression from avoidance to active information seeking, there was some variation in more granular aspects of the process. Participants spent different amounts of time at each stage and some repeated stages (some

parents cycled between avoidance and passive attention before moving to active seeking, whereas some progressed quickly from avoidance to active seeking). Examination of the factors that influence the rate and order of patient progress through the stages of information seeking would be useful to practitioners, social workers, and others who seek to support emotional and physical wellness after diagnosis.

## **Conclusion**

Patient and caretaker information seeking should be conceptualized as a progressive process, influenced over time by changing internal (cognitive and affective), behavioral, and external (situation and context) factors. This approach provides a basis for more holistic understandings of patient behavior and more responsive communication by medical professionals. In clinical settings, this supports long-term relationships between patients and care teams, better continuity of care, and can help professionals tailor health information to the needs of their patients.

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